Surveillance for Fetal Alcohol Syndrome in Wisconsin: Provider Education

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Purpose

- **Increase public awareness of FAS**
  - Describe the Wisconsin Fetal Alcohol Syndrome (FAS) Screening Project (WFASSP)
  - Identify the value of screening for FAS within the community
  - Demonstrate the different levels of screening for FAS
  - Provide referral sources for kids with possible FAS

Identify at risk children early and Intervene

FAS Facts

- First described in 1968-72
- Caused by alcohol intake during gestation
- Dose-response effect of alcohol use
- **No** known safe level of alcohol use during pregnancy
- Greatest contributor to preventable mental retardation

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Diagnosing FAS

1. **Maternal alcohol use during pregnancy**
2. **Growth retardation**
   - **Height/weight – less than 10th percentile**
   - **Intrauterine growth retardation and continued poor growth.**
3. **Facial malformations**
   (more than one, but not necessarily all)
   - **Short palpebral fissures**
   - **Abnormal philtrum**
   - **Thin upper lip**
   - **Hypoplastic midface**

Diagnosing FAS

4. Neurodevelopmental disorder

- Microcephaly
- Memory problems
- Attachment concerns
- Impaired motor skills
- Learning disabilities
- Problems with reasoning and judgement
- Inability to appreciate consequences of actions
- Intellectual impairment
- Delayed development
- ADD/ADHD
- Impaired visual/spatial skills
- Neurosensory hearing loss

Faces in FAS
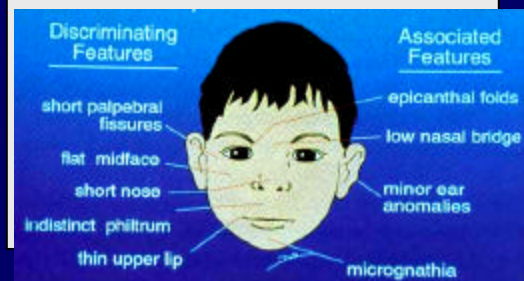
ARND – Alcohol related neurodevelopmental disorder
ARBD – Alcohol related birth defects

FAE – Fetal alcohol effects

Secondary Disabilities

- Mental health problems
- School failure
- Relationship problems
- Delinquency
- Difficulty with employment
- Difficulty with independent living

Problems in Ascertainment

- No diagnostic test
- No single trait diagnostic of FAS
- Broad range of expressivity
- Changes with age
- Behavioral profile may be most characteristic

Prevalence/Incidence Studies

- Estimates range from 0 to > 100 per 10,000 births/population
- Many different methods
- Samples are diverse
- Sample sizes vary greatly
- No universal standard for diagnosis

Purpose of 1997 CDC Grant: Population-based FAS Surveillance

- To document the magnitude (prevalence) of FAS in order to:
  - Monitor trends in occurrence
  - Document the impact of prevention efforts
- Implement provider education to improve ascertainment, referral, management and prevention of FAS

CDC Surveillance Case Definition
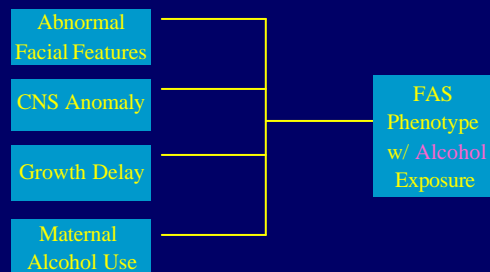
Binge Drinking Prevalence for Wisconsin and US Women 1990-2000 from the Behavior Risk Factor Surveillance System
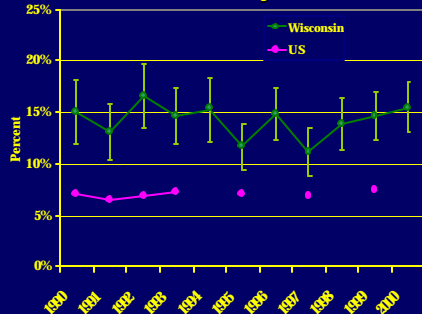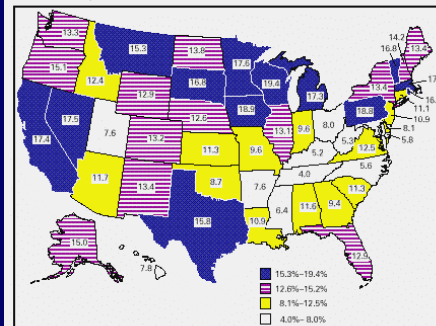

FIGURE 1. Prevalence of reported frequent alcohol consumption* among childbearing-aged women (18–44 years) — United States, Behavioral Risk Factor Surveillance System, 1995

*Consumption of an average of seven or more drinks per week or five or more drinks on at least one occasion during the preceding month.

Wisconsin FAS Screening Project Overview

- Four stage triage ascertainment system

- Begins with a full birth cohort from 1998 and 1999

- Includes all births from an 8 county region in southeastern Wisconsin (about 28,000 births per year)

Methodology

Screen 1: Select all Small for Gestational Age (SGA) infants in the birth cohort from the electronic birth files at the State Vital Records office.
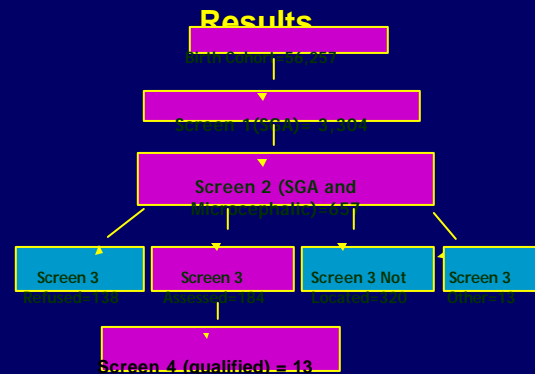
Screen 2: Select infants with microcephaly at birth (head circumference $< 10^{th}$ percentile) by abstracting the birth hospital records of Screen 1 (SGA) infants.

Methodology

Screen 3: Direct contact with subjects by letter/phone followed by visit to home or Marquette infant lab
- Growth, development, and facial features assessed
- If two or more facial features of FAS (flat philtrum, thin upper lip, small palpebral fissures) referred to next screening level

Screen 4: Expert dysmorphology assessment by geneticist at Children's Hospital of Wisconsin.


Results

Birth Cohort = 55,914

Screen 1 (SGA) = 3,904

Screen 2 (SGA and Microcephalic) = 657

| Screen 3 Refused = 1.98 | Screen 3 Assessed = 165 | Screen 3 Not Located = 326 | Screen 3 Other = 4 |

Screen 4 (qualified) = 13
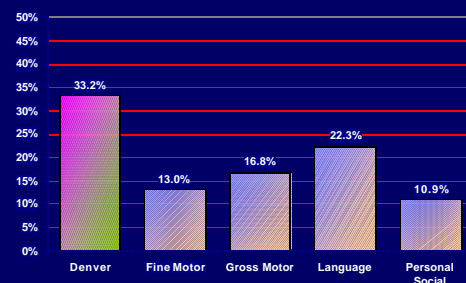
Results
Distribution of Risk Factors

- Children who qualified for Screen 2 (SGA + microcephaly) had greater reported rates of alcohol, drug, and cigarette use in comparison with the birth cohort.

- The Screen 3 children lost to follow up (not located plus refused) had increased risk in almost all variables assessed (e.g. late or poor prenatal care, < HS grad, increased substance use)

## Characteristic of Children Located in Screen 3

Screen 3 Growth Data: % of Children less than the 10th percentile

Height 19.0%, Weight 37.5%, Head Circumference 19.9%, Weight for Height 25.4%
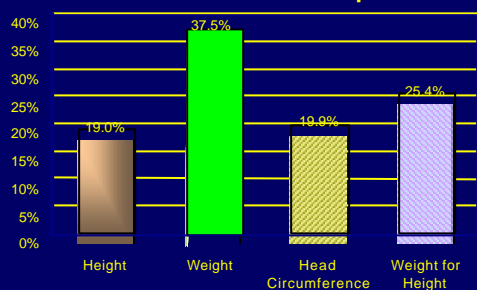
Percent of Children (N=184) with Suspect DENVER II and Delays per Subscales

Denver 33.2%, Fine Motor 13.0%, Gross Motor 16.8%, Language 22.3%, Personal Social 10.9%

Percent of Children with Delayed Development Recorded on One or More DENVER II Subscales (Total N=61)

One 33%, Two 39%, Three 18%, Four 10%
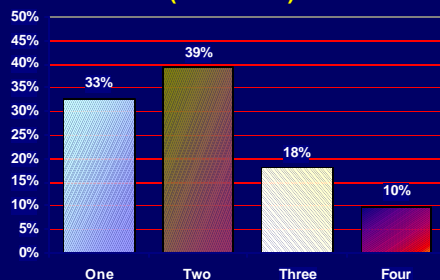
Key Findings

- ~30% of children screened found to have developmental delay, ~ 20-35% with growth delays

- Many receiving no intervention

- 13 children with facial features consistent with FAS had not previously been assessed for this syndrome.

  *As children lost to follow up were more at risk, these numbers may be under-reported

Summary

- In FAS, the key is early diagnosis, treatment, and provision of appropriate community services.

- With <u>early identification and treatment</u>, the neurodevelopmental disorder may be partially reversible.

- This study revealed a potential approach to population-based screening that could be used in the early identification of infants at risk for FAS as well as growth and developmental delay.

Screening Methods and Tools

Astley-Clarren Lip Philtrum Assessment Tool

Upper Lip and Philtrum

Abnormal: Numbers 4 or 5

Frankfort Horizontal Plane

Palpebral Fissures

Abnormal less than the 10th percentile

Normal vs. FAS

Referral Resources

- **Local Resources:**
  CHW - Dr. Mark Lubinsky, Genetics Clinic
  (414-266-3345)
  Family Empowerment Network (FEN)
  (1-800-462-5254) http://www.dcs.wisc.edu/pda/hhi/fen/

- **Web Sites:**
  http://www.wisc.edu/fasscreening/index.htm
  http://www.cdc.gov/ncbddd/fas/fassurv.htm
  http://depts.washington.edu.fasdpn/

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